Day two agenda: Community-Engaged Research Conference

Human Research Protection Office, Washington University School of Medicine in St. Louis

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Community-Engaged Research Forum
Community-Engaged Research: Exploring the unique community-academic relationship
Eric P. Newman Education Center (EPNEC)
Tuesday, September 27, 2011

7:00 – 8:00 am  Registration and Breakfast  EPNEC Main Auditorium

8:00 – 8:30 am  Welcome and Acknowledgements  EPNEC Main Auditorium
Bradley Evanoff, MD, MPH
Dr. Richard A. and Elizabeth Henby Professor of Occupational, Industrial and Environmental Science
Washington University School of Medicine

8:30 – 9:00 am  Keynote Address  EPNEC Main Auditorium
Challenges in Community-Engaged Research and Strategies to Overcome Them
Rick Kittles, PhD
Scientific Director and Co-founder of African Ancestry, Inc., Associate Professor of Medicine and Epidemiology and Biostatistics
University of Illinois at Chicago

9:00 – 10:30 am  Panel Discussion  EPNEC Main Auditorium
Facilitator
Consuelo H. Wilkins, MD, MSCI, Associate Professor, Department of Medicine, Geriatrics and Psychiatry, Co-Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science, Director of the Community Outreach Program in the Nutrition Obesity Research Center, Director of “Our Community, Our Health

Initial impressions, experiences, and coming together as a team
Lori Behrens, MSW, LCSW, Executive Director (SDS Resources) and Caroline Vemulapalli, Research Patient Coordinator (Washington University), St. Louis Community/University Health Research Partnership Award Recipients

Successes and failures: how to move forward
Christina Yongue Hardy, Community Research Fellow/Program Manager and Barbara Council, Community Expert Consultant, Community Based Participatory Research Charrette Process (University of North Carolina)

Keys to sustaining a long-term partnership
Loretta Jones, MA, founder and CEO of Healthy African American Families, Phase II (HAAF), Assistant Professor at Charles R. Drew University of Medicine and Science (CDU) and Aziza Lucas-Wright, MEd, Clinical Instructor, Charles Drew University of Medicine and Science

10:30 – 10:45 am  Break  EPNEC Lobby
Round Table Discussions will be lead by a facilitator and are designed to allow conference attendees to share experiences with others, network, and get potential ideas for forming or continuing a community-academic partnership. Framed in the context of new, intermediate, or long-term partnerships, attendees will share experiences with issues, as they apply, related to: Consent, Study conduct, Training, Trust, Financial issues, Sustaining the partnership, Challenges faced by the community partner, and potential areas where research could be done to fill a gap or void.

Lunch and Poster Presentations

**Networking Lunch**
For those that wish to engage in discussions and networking centering around specific types of community engaged research, please go to the designated EPNEC third floor rooms. Space is limited, please sign-up at the bar area.

**Leaders and research area of interest**

**EPNEC Room 305**
Sarah Gehlert, PhD – Cancer Research
Jane Garbutt, MB ChB and Mario Castro, MD, MPH – Asthma Research
Consuelo Wilkins, MD, MSCI – Geriatric Research

**EPNEC Room 306**
Brad Evanoff, MD – Occupational Research: “Ensuring the health of workers” (injury plus health promotion)
Monique Williams, MD, MSCI – Memory and Aging Research
Mitch Sommers, PhD – Psychology Research

**EPNEC Room 307**
Lori Behrens, MSW, LCSW and Caroline Vemullapalli – Pediatric Research
Hannah Reinhart, MS and Susan Racette, PhD - Nutrition and Physical Therapy
Building on conversations and presentations from earlier in the day, Think Tank sessions center around one issue relevant to community engaged research to provide a forum in which participants can discuss challenges and strategies to overcome them. Each discussion will be lead by a facilitator. A scribe will be present to take notes. At the end of the day, time is allocated for each group to share highlights from their discussions with the rest of the conference attendees.

**Think Tank Topics**

1. **Consent for community engaged research**  
   **EPNEC Main Auditorium**  
   Facilitators: Yvonne Joosten, MPH, Assistant Professor of Medical Education and Administration and Velma McBride Murray, PhD, Endowed Chair, Education and Human Development, Professor, Human and Organizational Development, Director, Center for Research on Rural Families and Communities and Co-Director, CTSA Community Engagement Research Core (Vanderbilt University)  
   I. Recruitment of patients (flyers vs phone vs in-person; role of community partnerships)  
   II. Consent of patients (readability and comprehension of consent materials, understanding of risks vs benefits)

2. **Study conduct issues**  
   **EPNEC Room 303**  
   Facilitators: Lauren Solberg, JD, MTS, Assistant Vice President of Human Subjects Protection and Research Integrity (Meharry Medical College) and Consuelo H. Wilkins, MD, MS CI, Associate Professor, Department of Medicine, Geriatrics and Psychiatry, Co-Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science, Director of the Community Outreach Program in the Nutrition Obesity Research Center, Director of “Our Community, Our Health (Washington University)”  
   I. Keeping partners engaged throughout the process  
   II. Dealing with “lack of trust” on the part of the partners  
   III. Developing feeling of shared ownership  
   IV. Addressing the community’s fear of litigation

3. **Training issues**  
   **EPNEC Great Room B**  
   Facilitators: Jane Garbutt, MB ChB, Research Associate Professor of Medicine and Pediatrics, Co-Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science and Director, WU PAARC and Mario Castro, MD, MPH, Professor of Medicine and Pediatrics, Adjunct Associate Professor of Community Health at St. Louis University School of Public Health (Washington University)  
   I. Training the community about research, e.g. randomization, controlled groups and use of in research methodology  
   II. Feelings of “ why do I need to spend the time doing the training.”  
   III. Developing research sophistication while maintaining relationships with the community
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1:00 – 3:00 pm     Think Tank Discussions     See Room Assignments below

4. Study design issues
Facilitators: Sarah Gehlert, PhD, E. Desmond Lee Professor of Racial and Ethnic Diversity and Director of the Center for Community-Engaged Research in the Institute of Clinical and Translational Science and Graham Colditz, MD, DrPH, Niess-Gain Professor of Surgery, Professor of Medicine; Chief, Division of Public Health Sciences, Department of Surgery; Associate Director, Prevention and Control, Alvin J. Stiehm Cancer Center; and the Deputy Director, Institute for Public Health, Washington University in St. Louis; Member, Institute of Medicine (Washington University)

   I. Helping partners to "lead the train" and not just follow so that community needs are met and the community does not feel used
   II. Building studies so that participants that are randomized or in the control groups have equal access to all research components at some point to avoid feelings of inequality amongst the participants
   III. Data collection and analysis: helping the community partner understand and accept this is a needed part of the study design
   IV. Constructing a Memorandum of Understanding (MOU)
   V. Negotiating Authorship

5. Financial issues
Facilitators: Russell Poland, PhD, Vice President for Research and Professor of Psychiatry and Behavioral Sciences (Meharry Medical College) and Bradley Evanoff, MD, MPH, Dr. Richard A. and Elizabeth Henby Professor of Occupational, Industrial and Environmental Science (Washington University)

   I. Full disclosure of what funding is available and how it will be shared by both the community partner and the academic investigator
   II. Lack of funding

6. Challenges faced by the community partner
Facilitators: Loretta Jones, MA, founder and CEO of Healthy African American Families, Phase II (HAAF), Assistant Professor at Charles R. Drew University of Medicine and Science (CDU) and Aziza Lucas-Wright, MEd, Clinical Instructor (Charles Drew University of Medicine and Science)

   I. Lack of time to initiate and participate in research activities
   II. Developing the research sophistication needed to participate fully
7. Sustainability once the initial funding concludes  
Facilitators: Christina Yongue Hardy, Community Research Fellow/ Program Manager and Barbara Council, Community Expert Consultant, Community Based Participatory Research Charrette Process (University of North Carolina)

I. Should be part of the planning process  
II. How to build community resources  
III. What happens once initial funding ends

8. Research gaps and ideas for potential research partnerships  
Facilitators: Hannah Reinhart, MS, Community Development Coordinator (Gateway Greening) and Susan Racette, PhD, Associate Professor, Physical Therapy, Department of Medicine—Division of Geriatrics and Nutritional Science and Department of Medicine—Division of Endocrinology, Metabolism & Lipid Research (Washington University)

I. Where does the community see the need for conduct of research  
II. Within existing programs/services, etc.  
III. To develop new programs/services, etc.

3:00–3:15 pm  Time to prepare reports from Think Tank sessions

3:15–3:45 pm  Reports from Think Tank Discussions  
Brenda Battle, MBA  
Director, Center for Diversity and Cultural Competence  
Barnes-Jewish Hospital Diversity and Cultural Competence

3:45 pm  Closing and Evaluation  
Bradley Evanoff, MD, MPH  
Dr. Richard A. and Elizabeth Henby Professor of Occupational, Industrial and Environmental Science  
Washington University School of Medicine

4:00 pm  Deadly Medicine: Creating the Master Race  
Browse through an exhibit by the United States Holocaust Memorial Museum